Journal of Pediatric Nursing (2014) **29**, 29–38

# Sleep Quality, Stress, Caregiver Burden, and Quality Of Life in Maternal Caregivers of Young Children With Bronchopulmonary Dysplasia

**Christine A. Feeley PhD, RN [a,c,*], Anne Turner-Henson DSN, RN, FAAN [a], Becky J. Christian PhD, RN [a], Kristin T. Avis PhD [b], Karen Heaton PhD, RN [a], David Lozano MD [b], Xiaogang Su PhD [a]**

[a] *University of Alabama at Birmingham School of Nursing, Birmingham, AL*
[b] *UAB Department of Pediatrics at Children's of Alabama, Birmingham, AL*
[c] *Emory University Nell Hodgson Woodruff School of Nursing, Atlanta, GA*

**Key words:**
Caregiver;
Sleep quality;
Stress;
Burden;
Quality of life;
Bronchopulmonary dysplasia;
Children

Little is known about the influence of sleep quality, stress, and caregiver burden on quality of life in maternal caregivers of young children with bronchopulmonary dysplasia (BPD). In 61 maternal caregivers (mean age 29.59 years) of young children with BPD (mean age 13.93 months), caregivers reported sleeping a mean of 5.8 hours, and significant correlations were found between sleep quality and depressive symptoms and stress, as well as an inverse correlation with quality of life. Sleep quality was found to be the most significant predictor of quality of life in maternal caregivers.

WHILE RECENT ADVANCES in healthcare treatments of premature or chronically ill infants have led to increased survival rates, these infants are still at risk for developing chronic illnesses, such as bronchopulmonary dysplasia (BPD) (Gracey, Talbot, Lankford, and Dodge, 2002). The rates of BPD have decreased over the past 5 years due to advanced treatments, however the acuity and healthcare expenditures for these infants and children has increased, especially as infants with BPD are spending a longer time in the NICU and requiring more complex care at home (Stroustrup and Trasande, 2010). The National Heart, Lung, and Blood Institute (NHLBI) reported that nearly 1 in 3 infants born with very low birth weight (VLBW) (less than 1,500 grams) will be diagnosed with BPD (National Heart Lung Blood Institute, 2009). Gracey and colleagues reported that an estimated 7,200 new cases of BPD will be diagnosed each year, and the majority of these cases are the result of healthcare treatments (e.g., ventilation, requiring oxygen) or lung immaturity.

Upon hospital discharge, many of these infants will have multiple co-morbidities and are sent home with complex health care treatment regimens. The primary caregiver, usually the mother, is ultimately responsible for providing the health care treatments, monitoring the child and the child's equipment, and general physical care of the child while at home (Sawyer et al., 2011). However, mothers may have received little to no preparation prior to the child's discharge. Thus, the consequences of providing relentless care on the mother are possibly far-reaching, influencing several aspects of her quality of life, and influencing the family (Singer, Salvator, and Gua, 1999). Caregivers of chronically ill children often report poor sleep quality, and stress and burden may be high, leading, possibly, to overall poor quality of life (QOL) (Klassen et al., 2008; Meltzer and Mindell, 2006). However, little is known about how sleep, caregiver burden, and stress may influence quality of life in maternal caregivers of young children with BPD.

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* Corresponding author: Christine A. Feeley, PhD, RN.
*E-mail address:* cfeeley@emory.edu.

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http://dx.doi.org/10.1016/j.pedn.2013.08.001

## Review of the Literature

BPD is a chronic illness, most commonly found in premature infants as a result of immature lungs or treatments in the NICU (such as ventilation or oxygen administration) (Gracey et al., 2002). Although the definition of BPD has undergone several changes throughout the years (Gracey et al., 2002), most health providers now use the definition proposed by the NIH, National Institute of Child Health and Human Development, the NHLBI, and the Office of Rare Diseases (Jobe and Bancalari, 2001). This definition encompasses mild, moderate, and severe BPD, classified mainly by the child's need for oxygen after she or he has been sent home or after birth, and helps to guide treatment decisions. The more severe forms of BPD require greater oxygen while at home and possibly CPAP (Jobe and Bancalari, 2001).

Home healthcare treatment regimens for children with BPD often involve home oxygen therapy, pulse oximetry monitoring, specialized nutrition plans, complex medication schedules, nebulizer breathing treatments, and other therapies such as physical or occupational therapy due to developmental delays (Deakins, 2009; Holditch-Davis, Docherty, Miles, and Burchinal, 2001; Singer et al., 2010). Maternal caregivers of young children with BPD may be at risk for increased levels of stress, caregiver burden, depressive symptoms, and poor sleep due to maintaining their child's health and managing this complex care. This combination of elevated stress and caregiver burden, elevated depressive symptoms, combined with poor sleep quality, may result in decreased levels of QOL, as demonstrated in other caregivers of children with a chronic illness or condition (Cummings et al., 2010; Klassen et al., 2008; Singer et al., 2010). Caregivers of children with BPD have reported increased levels of stress and anxiety, especially pre-discharge when the child required in-home oxygen therapy (Zanardo and Freato, 2001). Zanardo and Freato found that anxiety was at its highest before discharge, and in the immediate period after bringing the child home, but would decrease as the child's condition improved, or the need for in-home oxygen therapy ended, as caregivers became more comfortable providing treatments.

Singer et al. (2010) found that mothers of children born very low birth weight and diagnosed with BPD, reported higher levels of stress and parenting stress than mothers of term infants, especially during the first 3 years of life. However, by school age, levels of stress were equal, as mothers of term children reported increasing stress levels. This may be due to the onset of adolescence, a typically stressful period of development for both parent and child (Singer et al. (2010)).

Little is known about caregiver burden in maternal caregivers of young children with BPD. However, elevated stress and anxiety have been positively associated with higher levels of caregiver burden in parental caregivers of children requiring home enteral nutrition (Calderon et al., 2010). Similarly, in parental caregivers of young children with cancer, decreased caregiver strain was found to be related to increased health-related QOL (Klassen et al., 2011). In fact, caregivers' strain was found to be one of the most important determinants of the parent's QOL, as well as parental health (e.g., lower caregiving demands were associated with elevated caregiver health scores) (Klassen et al., 2011). These findings suggest that caregiver burden and stress influence overall QOL in caregivers.

Sleep quality has not been assessed in maternal caregivers of young children with BPD. However, maternal caregivers of young children with BPD may be at risk for poor sleep for a number of reasons, including elevated feelings of anxiety (Zanardo and Freato, 2001), equipment alarms at night, needing to change formula bags, medications or treatments to be given at night, along with child awakenings (Deakins, 2009; Singer, Yamashita, Lilien, Collin, and Baley, 1997). Previous literature on children with chronic illnesses and conditions has found that caregivers often report poor sleep quality and restricted sleep duration (sleeping between 4–6 hours per night) (Cottrell and Khan, 2005; Meltzer, Boroughs, and Downes, 2010; Meltzer and Mindell, 2006). Poor sleep quality has also been associated with increased feelings of stress and elevated anxiety in maternal caregivers of young children with developmental disabilities (Gallagher, Philips, and Carroll, 2010). Stress and burden from the myriad of responsibilities and tasks associated with caring for a young child with BPD may also influence QOL (Mitchell, 1996). However, little is known about the relationship between sleep quality, stress, caregiver burden, and QOL in caregivers of young children with BPD (Monaghan, Hilliard, Cogen, and Streisand, 2009; Zanardo and Freato, 2001).

## Framework

Lazarus and Folkman's theory of stress, appraisal, and coping was used as the framework for this study. In relation to Lazarus and Folkman's (1984) theory, sleep quality and caregiver burden have been shown to influence stress in maternal caregivers, and may act as antecedents to the maternal caregiver's appraisal of the situation (Fletcher et al., 2008; Gallagher et al., 2010). Sleep quality may influence how the maternal caregiver perceives her interaction with her environment and how she perceives her child's needs or care. Poor sleep quality may influence the maternal caregiver to report increased stress; and therefore, view her interaction with the environment as a threat, rather than a challenge (a challenge having a more positive connotation) (Carter, 2003, 2006; Gallagher et al., 2010; Meltzer, 2008). In the same way, the caregiver's burden may also influence how the mother perceives her interaction with her environment, and as with sleep quality, may influence the maternal caregiver to report increased stress (Brehaut et al., 2004; Raina et al., 2005). Sleep quality and caregiver burden may act as antecedents to appraisal and influence stress levels, while QOL is considered an outcome (Arafa, Zaher, El-Dowaty, and Moneeb, 2008; Lazarus & Folkman).

The overall research question was: Do sleep quality, stress, and caregiver burden influence overall QOL in maternal caregivers? The specific aims are as follows: 1) Describe the sleep quality, caregiver burden, stress, depressive symptoms, and QOL in maternal caregivers of young children with BPD; 2) determine the relationships between sleep quality, caregiver burden, stress, and QOL in maternal caregivers of children with BPD; 3) examine the influences of QOL on age, depressive symptoms, education, marital status, sleep quality, caregiver burden, and stress; 4) determine if stress mediates the relationship between sleep quality, caregiver burden and QOL in maternal caregivers of young children with BPD.

## Methods

### Design

A non-experimental, descriptive, correlational, cross-sectional design was used in a sample of maternal caregivers of young children with BPD who were recruited from a large, specialty clinic in a pediatric hospital in the Southeast. This study was approved by the university Institutional Review Board prior to the onset of the study. A convenience sample was recruited over a 6-month period.

### Sample

The maternal caregiver was defined as the self-identified, primary female caregiver. To be included in the study, the maternal caregivers were over the age of 16 years, able to read, write, and understand English, and not have a diagnosed history of a sleep disorder (obstructive sleep apnea, restless leg syndrome, insomnia). The child with BPD had to be diagnosed with moderate BPD, living at home with the maternal caregiver for at least 2 months, not require a ventilator or tracheotomy, and between the ages of 4 months and 3 years. In order to be referred to the specialty BPD clinic used for this study, the child had to meet certain requirements, including the need for oxygen via nasal cannula while at home and requiring diuretics (e.g., Lasix or Aldactone). A power analysis was conducted and an effect size was calculated based on previous literature using the same outcome measurement World Health Organization's Quality of Life Brief (WHO QOL-BREF). With a calculated effect size of .39, a power of 90, and an alpha set at .05, the total estimated sample size needed was 60 maternal caregivers. During the child's clinic visit, if the child and maternal caregiver met study inclusion criteria, as screened by a clinic nurse, they were approached by the principal investigator to discuss participation in the study, and the consent process was begun.

### Instrumentation

Demographic data were collected on maternal caregiver's age, race, educational attainment, and marital status, other individuals living at home with the maternal caregiver and child. Data on the child included the child's age, and how long the child had been living at home with the maternal caregiver. The maternal caregiver completed all self-report, paper and pencil questionnaires while with the child in a private clinic room.

### Sleep Quality

The Pittsburgh Sleep Quality Index (PSQI) is a measure of subjective sleep quality, consisting of 19 questions on a 4-point scale, with responses ranging from "not during the past month," to "three or more times a week." The PSQI has a global measure, as well as seven subscales (not included in this analysis) (Buysse, Reynolds, Monk, Berman, and Kupfer, 1989). Only the global score was used for this study, and a score of 5 or greater indicates clinically disturbed sleep (Buysse et al., 1989). Aslan et al. (2009) reported a Cronbach's alpha of 0.82 in a study of parental caregivers of children with cancer. The observed Cronbach's alpha for this study was 0.83 for the global scale.

### Perceived Stress

The perceived stress scale (PSS) is a measure of perceived stress based on Lazarus and Folkman's (1984) conceptual model of stress appraisal, (Golden-Kreutz, Frierson, & Anderson, 2004). The PSS is a 10-question, self-report questionnaire, Likert scale, with six of the items being negative (i.e., "In the last month, how often have you felt nervous or stress?") and the four remaining questions being reverse scored and more positive (i.e., "In the last month how often have you felt things were going your way?") (Cohen, Kamarck, and Mermelstein, 1983). A higher score indicates higher stress. Cronbach's alpha for the PSS was reported as 0.84 in a study of parental caregivers of children with peanut and nut allergies (King, Knibb, and Hourihane, 2009). The observed Cronbach's alpha for this study was 0.72.

### Caregiver Burden

Caregiver burden was measured using the Montgomery-Borgatta Caregiver Burden Scale-Revised (MBCBS-R) (Savundranayagam, Montgomery, and Kosloski, 2010). The objective burden subscale was used as measure of burden in this study. This measure is 22 items on a 5-point Likert scale with four subscales (stress burden, relationship burden, objective burden, and an uplifts scale) (Savundranayagam et al., 2010). A higher score indicates a higher level of burden. The MBCBS-R is relatively new, but has shown good reliability in caregivers of adult family members (Cronbach's alpha ranging from 0.89 to 0.93) (Savundranayagam et al., 2010). This measure has not been used in caregivers of children. The observed Cronbach's alpha for this study was 0.88 for the objective subscale. The 4 subscales ranged from a Cronbach's alpha of 0.77–0.88.

### Quality of Life

Quality of life was measured using the WHO QOL-BREF (World Health Organization, 1998), a 26-item instrument on a 5-point Likert scale, with responses ranging from "never" to "always." The instrument is a general measure of QOL used internationally and has been validated in adult populations (World Health Organization). A higher score indicates better QOL. The WHO QOL-BREF includes four domains (physical, psychological, relationships, and environmental). The WHO QOL-BREF has been used in parental caregivers of children with peanut and nut allergies, with reported Cronbach's alphas ranging from .80 to .82 (Chien, Lo, Chen, Chen, Chiang, and Chao, 2003). The instrument has established discriminate validity with the longer, more in-depth QOL questionnaire, the WHO QOL-100 (World Health Organization). The observed Cronbach's alpha for this study was 0.88, with a range of 0.83–0.88 for all four domains.

### Depressive Symptoms

The Center for Epidemiological Studies Depression Scale (CES-D) was used to assess depressive symptoms, a confounding variable, in maternal caregivers. The CES-D is a measure of depression that was designed to be used in a general population of healthy adults (Radloff, 1977). The CES-D is a 20-item, 4-point Likert measure that assesses current levels of depressive symptoms, including depressed mood, feelings of guilt, worthlessness, loss of appetite, and psychomotor retardation (Radloff, 1977). This instrument has been used in caregivers of children with a chronic condition, with a reported Cronbach's alpha of 0.86 (Meltzer and Mindell, 2006). The observed Cronbach's alpha for this study was 0.77.

### Sample Demographic Data

A total of 61 maternal caregivers of children with BPD were enrolled in the study over a 6-month period. Fifty-nine (96.7%) identified as the mother, while two (3.3%) identified as the grandmother. Forty-one were African American (67.2%) and 20 were Caucasian (32.8%). As shown in Table 1, the majority of the sample were single, never married, and had graduated from high school. The mean age of the maternal caregivers was 29.59 years, with a range of 17 to 50 years. Thirty-two (52.5%) caregivers reported having the father living with them. The mean age of the child with BPD was 13.93 months (range of 4 to 36 months), and the child had been living at home for a mean of 8.79 months (range of 2–36 months). Table 1 displays home characteristics for the sample.

## Results

The PSQI global scores ranged from 0 to 17, with a mean of 7.62 (*SD* = 3.72). The perceived stress scale scores ranged from 2 to 26, with a mean of 18.34 (*SD* = 4.73), and the MBCBS-R objective subscale scores ranged from 7 to 29 (mean of 17.41 and *SD* = 5.99). The WHO QOL-BREF scores ranged from 26 to 130, with a mean of 90.4 (*SD* = 10.74). The CESD scores ranged from zero to sixty, with a mean of 10.53 (*SD* = 8.06).

### Descriptive Statistics, Aim 1: Describe Sleep Quality, Caregiver Burden, Stress, Depressive Symptoms, and QOL in Maternal Caregivers of Young Children With BPD

Maternal caregivers reported sleeping a mean of 5.8 hours a night (range = 1 to 10 hours a night, *SD* =

**Table 1** Demographic and Home Characteristics of the Sample (*N* = 61).

| Maternal Caregiver Characteristics | *n* | % |
|---|---|---|
| Education status | | |
| Some high school | 7 | 11.5 |
| High school graduate | 16 | 26.2 |
| Some college | 24 | 39.3 |
| College graduate-Associates | 2 | 3.3 |
| College graduate- Bachelors | 5 | 8.2 |
| Masters/Graduate degree | 7 | 11.5 |
| Relationship Status | | |
| Married | 23 | 37.7 |
| Single- never married | 34 | 55.7 |
| Divorced | 2 | 3.3 |
| Separated | 2 | 3.3 |
| HOME CHARACTERISTICS | | |
| Those living in the home with mother and child | | |
| Father of child | 32 | 52.5 |
| Grandmother of child | 13 | 19.7 |
| Grandfather of child | 2 | 3.3 |
| Aunt of child | 2 | 3.3 |
| Number of Siblings in the home | | |
| 0 | 25 | 41 |
| 1 | 17 | 27.9 |
| 2 | 12 | 19.7 |
| 3 | 5 | 8.2 |
| 5 | 1 | 1.6 |
| 7 | 1 | 1.6 |

Note: Some maternal caregivers did not report having anyone else living with them in the home, while others may report more than one person (grandmother and father).

1.7). The majority (68.8%, $n = 42$) of caregivers reported 6 or fewer hours of sleep, with 42.6% ($n = 26$) reporting less than 5 hours, and 21.3% ($n = 13$) reporting 4 or less hours of sleep a night. Thirty-one (50.8%) maternal caregivers reported their overall sleep quality as fairly good, ten (16.4%) reported their overall sleep quality as very good, nineteen (31.1%) reported it as fairly bad, and one (1.6%) reported it as very bad. Maternal caregivers reported taking a mean of 37.8 minutes to fall asleep (range of 1 minute to 4 hours, $SD = 41.06$ minutes). The majority of maternal caregivers (78.7%, $n = 48$) reported a global sleep score of 5 or above, indicating clinically disturbed sleep (Buysse et al., 1989).

## Correlations, Aim 2: Determine Relationships Between Sleep Quality, Caregiver Burden, Stress, and QOL in Maternal Caregivers of Children With BPD

Pearson's product–moment correlations were computed to assess relationships among the continuous study variables, and a Bonferroni correction was used due to the number of comparisons done (alpha set at .05 divided by 10 comparisons yielded a corrected alpha of .005 with Bonferroni correction). Table 2 reports the Pearson correlation values, with asterisks indicating significance at the .05 and .005 level.

Significant relationships were found between stress and QOL ($r = .101$ $p \le .05$), caregiver burden ($r = .326$ $p \le .05$), sleep quality ($r = .284$, $p \le .05$), and years of maternal education ($r = .317$, $p \le .05$) and also between sleep quality and quality of life ($r = -.292$, $p \le .05$), and depressive symptoms ($r = .529$, $p \le .005$). Other significant correlations included depressive symptoms and caregivers age ($r = -.146$, $p \le .05$), and child's age ($r = .297$, $p \le .05$), as well as child's age and time the child has been at home ($r = .890$, $p \le .005$).

## Multiple Linear Regression, Aim 3: Examine the Influences of QOL on Age, Depressive Symptoms, Education, Marital Status, Sleep Quality, Caregiver Burden, and Stress

Using forced entry multiple linear regression, with a sample size of 61, the overall model is presented in Table **3**, with all independent and dependent variables included. To determine the best model, changes in R squared were assessed using three steps. The independent variables of sleep quality, stress, and caregiver burden were entered first, then the covariate of depressive symptoms was entered in step two, then the other demographic covariates were entered (maternal caregiver's age, education level, relationship status, and race) for step three. The categorical covariates of education level (high school or greater and less than high school), relationship status (married or single), and race (black or white) were collapsed and entered as binary variables. Table 3 displays the overall model, with all variables shown.

Model 2 (Table 4) was determined to be the best model with the most significant change in R squared (sig F change = .025, adjusted R square = .222), explaining 22% of the variance. Sleep quality (beta $= -.552$; $p \le .000$) and depressive symptoms (beta $= .322$; $p \le .025$) were found to be the most significant predictors of QOL in maternal caregivers of young children with BPD in model 2.

## Mediation, Aim 4: Determine if Stress Mediates the Relationship Between Sleep Quality and Caregiver Burden and QOL in Maternal Caregivers of Young Children With BPD

Mediation was measured using Baron and Kenny's (1986) four-step method, with an alpha set at .05. In the first step, sleep quality and caregiver burden were examined

**Table 2** Pearson's Correlation Matrix of the Major Variables.

| Variable | Cg age | Child's Age | Sibling | Time Home | Dep Symp | Yrs Ed | Stress | Sleep Quality | Cg Burden |
|---|---|---|---|---|---|---|---|---|---|
| Cg age | - | | | | | | | | |
| Child's age | .052 | - | | | | | | | |
| Sibling | .164 | .051 | - | | | | | | |
| Time home | −.015 | .890 ** | .075 | - | | | | | |
| Depressive symptoms | –.146 * | .297 * | .175 | .405 ** | - | | | | |
| Years ed | .079 | –.389 ** | –.188 | –.337 | –.030 | - | | | |
| Stress | .016 | –.077 | –.360 * | .003 * | .092 | .317 * | - | | |
| Sleep quality | .055 | .228 | .143 | .277 | .529 ** | .049 | .284 * | - | |
| Cg burden | –.170 | –.079 | –.235 | –.051 | .087 | .236 | .326 * | .233 | - |
| QOL | .079 | –.185 | –.169 | –.144 | .061 | .214 | .101 * | –.292 * | .133 |

Note: $N = 61$ for all correlations. Cg = maternal caregiver, QOL = quality of life, dep symp = depressive symptoms, siblings = number of siblings in the home, Yrs ed- years of maternal education.

* $p \le .05$.

** $p \le .005$ (Bonferroni corrected alpha).

**Table 3** Overall Model Using Major Variables ($N = 61$).

| | Unstandardized Coefficients | | Standard Coefficient | $t$ | $p$ | Collinearity Statistics | |
|---|---|---|---|---|---|---|---|
| | B | Std. Error | Beta | | | Tolerance | VIF |
| (Constant) | 3.099 | .478 | | 6.487 | .000 | | |
| Stress | .017 | .011 | .206 | 1.538 | .131 | .721 | 1.387 |
| Sleep quality | −.059 | .016 | −.542 | −3.757 | .000 * | .622 | 1.609 |
| Objective burden | .011 | .008 | .174 | 1.327 | .191 | .754 | 1.327 |
| Depressive symptoms | .019 | .007 | .384 | 2.635 | .011 * | .607 | 1.648 |
| Cg age (yrs) | .013 | .007 | .252 | 1.864 | .068 | .707 | 1.414 |
| Education | −.284 | .156 | −.222 | −1.818 | .075 | .867 | 1.154 |
| Married or not | .304 | .129 | .380 | 2.358 | .052 | .496 | 2.014 |
| Dad at home | .054 | .074 | .095 | .723 | .473 | .752 | 1.330 |
| BPD mother's first | −.018 | .105 | −.023 | −.174 | .863 | .717 | 1.395 |
| Race | −.126 | .126 | −.154 | −.993 | .325 | .537 | 1.861 |

Note: Dependent variable: QOL.

* $p < .05$.

as predictors of QOL, with simple regression conducted separately for both variables to predict QOL. Step 2 assessed stress as the outcome variable. Simple linear regression was used, with sleep quality as a predictor of stress, and caregiver burden as a predictor of stress (the mediator variable being tested). Then, in step 3, simple linear regression was run, to determine if stress, the mediating variable, significantly predicted QOL. Finally, in step 4, sleep quality and stress were placed in the same model to predict QOL, then caregiver burden and stress were placed in the same model to see if either showed any significant prediction of QOL.

Stress was not found to be a mediating variable for sleep quality and caregiver burden to QOL with an alpha set at .05. Caregiver burden was found to be a significant ($t = .2644$, $p = .010$) predictor of stress, but not QOL. Sleep quality was found to be significant as a predictor of QOL ($t = -2.345$, $p = .022$), and stress ($t = 2.275$, $p = .027$). And finally, stress was not found to be a significant predictor of QOL ($t = .779$, $p = .439$). In order for stress to be a mediating variable, caregiver burden and sleep quality must have a significant relationship with QOL. Likewise, caregiver burden and sleep quality must also have a significant relationship with stress. Stress, must also have a significant relationship with QOL, the overall outcome variable. Thus, the steps and requirements for mediation were not satisfied.

## Discussion

In this study of maternal caregivers of young children with BPD, sleep quality and depressive symptoms were significant predictors of QOL. Multiple linear regression forced entry method was used with a sample of 61 maternal caregivers to evaluate influences on QOL in maternal caregivers. In the overall model, and based on the standardized coefficients, sleep quality had the greatest influence on QOL followed by depressive symptoms. Sleep quality emerged as the only independent variable to significantly predict QOL in maternal caregivers of young children with BPD. Depressive symptoms, as a covariate, were also significant as a predictor of QOL.

### Sleep Quality

In this study, maternal caregivers reported, on average, 5.8 hours of sleep per night, which is similar to other studies

**Table 4** Multiple Linear Regression Using Model 2.

| | Model 2 | | | | | | |
|---|---|---|---|---|---|---|---|
| | Unstandardized Coefficients | | Standardized Coefficients | $t$ | $p$ | Collinearity Statistics | |
| | B | Std. Error | Beta | | | Tolerance | VIF |
| Constant | 3.593 | .203 | | 17.720 | .000 | | |
| Cg Burden | .011 | .008 | .178 | 1.411 | .164 | .872 | 1.147 |
| Sleep Quality | −.057 | .015 | −.552 | −3.777 | .000 * | .650 | 1.539 |
| Stress | .014 | .010 | .170 | 1.326 | .190 | .845 | 1.183 |
| Depressive Symptoms | .015 | .007 | .322 | 2.312 | .025 * | .716 | 1.398 |

* $p$-value ≤ .05.

of caregivers of children with a chronic illness or ventilator dependency (Cottrell and Khan, 2005; Meltzer and Mindell, 2006). Less than 6 hours of sleep per night is not recommended, because deficits in cognitive functioning (especially memory), and response times (reflexes) have been found (Pilcher and Huffcutt, 1996; Stenuit and Kerkhofs, 2008). The mean global sleep score for maternal caregivers of children with BPD was elevated (mean = 7.6), which is reflective of elevated scores in previous studies with maternal caregivers of young children with developmental disabilities (Gallagher et al., 2010) and of children on a ventilator (Meltzer and Mindell, 2006), and higher than caregivers of healthy children (Meltzer and Mindell, 2006). As seen in this study, maternal caregivers of children with BPD reported slightly better sleep than other caregivers; however, the average was still above five, which is the reported PSQI scale cut-off for clinically disturbed sleep (Buysse et al., 1989). This suggests that providing care for a child with moderate BPD results in poorer sleep quality and disturbed sleep (Buysse et al., 1989). This may be due to a number of reasons, including the acuity and chronicity of the child's illness and prognosis (Deakins, 2009; Meltzer & Mindell).

Poor sleep was moderately associated with greater depressive symptoms and stress, suggesting that sleep quality influences several aspects of the caregiver's life. Significant relationships among sleep quality, stress, depressive symptoms, and QOL have been demonstrated in previous research of caregivers of children with a chronic illness or condition (Chien et al., 2003; Gallagher et al., 2010; Meltzer and Mindell, 2006). Depressive symptoms have been shown to be significantly correlated to QOL in caregivers, and may be important indicators of a maternal caregivers overall well-being (Tsai et al., 2012). Of the independent variables measured, sleep quality was the only variable that showed a significant relationship with the outcome variable, QOL. This is reflective of previous research in this area that demonstrated that sleep quality is associated with QOL in maternal caregivers of children with cancer (Klassen et al., 2010).

## Caregiver Burden

Caregiver burden was assessed for this sample using the objective subscale of the MBCBS-R (Savundranayagam et al., 2010). Although this instrument has not been used previously in studies of caregivers of young children with a chronic illness or condition, to date, there are no general caregiver burden scales for caregivers of young children with a chronic condition or illness. Therefore, a general measure was chosen that had been used in samples of adult caregivers to adult family members.

In this study, there was a significant positive correlation between stress and caregiver burden; that is, maternal caregivers' reports of increased stress were associated with higher levels of caregiver burden. Few studies have examined stress and caregiver burden in caregivers of chronically ill children. Calderon and colleagues (2010) found caregiver burden to be associated with increased levels of stress in caregivers of young children requiring enteral nutrition. While a different population from children with BPD is used in this study, the findings reflect how caregivers may feel in relation to caring for a child that requires care, but is not acute enough to warrant professional in-home help.

## Stress

In this study, maternal caregivers had a mean PSS score of 18.34 (*SD* = 4.73). In contrast, stress scores were higher than the scores in this study for caregivers of young children with peanut allergies (King et al., 2009). The mean PSS score was 25.13 (*SD* = 6.67) (King et al., 2009), much higher than this sample, and the normalized sample from the United States (mean of 16.14 for adult, healthy women) (Cohen et al., 1983). Parent caregivers of a school-aged child with a peanut allergy may feel increased stress as their child starts making individualized, autonomous food decisions at school.

In this sample of maternal caregivers of young children with BPD, greater stress was weakly but significantly correlated with increased caregiver burden and poorer sleep quality, but not QOL. This suggests that higher stress levels may have a greater influence on sleep than overall QOL. The significant correlation with sleep quality supports previous literature in caregivers of children with diabetes (Monaghan et al., 2009) and caregivers of children with a developmental disability (Gallagher et al., 2010). Maternal caregivers reporting increased stress were also likely to report having the child in the home for a longer period of time. Reports of increased stress due to having the child home for a longer period of time may be related to the similar finding of increased stress being related to increased caregiver burden (Calderon et al., 2010).

Children with chronic conditions such as BPD often require complex caregiving in the home, having a great impact on the family, predominately from the mother who is often the primary caregiver for the child (Holditch-Davis, Miles, Burchinal, and Goldman, 2011). Mothers most often provide healthcare treatments, monitoring, and general physical care of the child while at home (Singer et al., 2010). Often, maternal caregivers report poor sleep quality, and high stress and caregiver burden, leading, to overall poorer QOL (Arafa et al., 2008; Klassen et al., 2008; Meltzer, 2008). In this study, maternal caregivers reported poor sleep quality, high levels of stress, high caregiver burden and poor QOL.

## Limitations

Several limitations should be noted for this study. The sampling method was a convenience sample of maternal caregivers of young children with BPD. A bias may be present, as maternal caregivers had to volunteer to be in the study, so those who agreed to participate may be different from those who declined (Polit and Beck, 2008).

While the use of sleep medications was used as an exclusion criterion, the medication history of the maternal caregiver was not assessed, and may have had an impact on the maternal caregiver's sleep (Clark, Flowers, Boots, and Shettar, 1995; Redline, Kirchner, Quan, Gottlieb, Kapur, and Newman, 2004). Other influences on sleep that were not assessed include the maternal caregiver's menopausal state, smoking status, alcohol use, and the sleeping environment (bed partner) (Rittman, Hinojosa, and Findley, 2009; Shaver, 2002).

The variable caregiver burden was measured using the MBCBS-R, which had never been used in caregivers of young children, and in fact, the revised version has only had limited use in caregivers of adults (Savundranayagam et al., 2010). However the internal consistency of the caregiver burden scale demonstrated high reliability. Only the objective burden subscale was used for this study. Hence, the MBCBS-R was used in this study in a non-standardized manner. The continued use of this measure in different populations may lend more reliability and validity data to support it.

The findings may be influenced as self-report measures are subjective and require the maternal caregiver to remember and report accurately. Social desirability may have also been a limitation. Some caregivers may not want to report feeling their child is a "burden" or may not want to seem as if having their child is a "stressor," and so may not accurately reflect their feelings on a questionnaire (Polit and Beck, 2008). However, all maternal caregivers were told that their information would be kept confidential, and all data were anonymous.

## Implications for Practice

Maternal caregivers in this study reported poor sleep quality, reporting on average 5.8 hours a night sleeping, suggesting that they may be chronically sleep deprived. Healthcare providers of children with chronic conditions need to assess sleep habits of maternal caregivers. Assessments should include not only the hours of sleep, but sleep environments and other caregiving and environmental factors that influence sleep quality, such as napping, and the child's sleep schedule. The importance of establishing a bedtime routine, and limiting the sleeping environment to sleep (not watching television in bed) are important topics to discuss with maternal caregivers of young children with BPD.

Maternal caregivers often provide relentless and intense care for their children that may occur during their regular sleep hours (McCann, Bull, and Winzenberg, 2012). When possible, coordination of the child's care (such as scheduling medications or breathing treatments) outside of normal sleeping hours should be done so that it does not interfere with the maternal caregiver's sleep. Coordinating care across providers is also needed, as many of these children see a variety of health care practitioners. Providers need to assess the caregiver's daily routines at home, including time for sleep and rest. If respite care is available and accessible for the caregivers, health care providers should discuss and educate parents who may not know that respite care exists. Similar to other studies, this study has future implications for the need for respite care or supportive care for these caregivers, allowing for them to have time to sleep or nap, if uninterrupted nighttime sleep is impossible (Meltzer et al., 2010). Also, ensuring that the maternal caregiver receives adequate training and education, and is aware of how to monitor the child's condition may help her to feel a greater sense of empowerment, which may help to alleviate feelings of stress and caregiver burden (Nachshen and Minnes, 2005).

## Recommendations for Future Research

Building on the results of this study and the variable of sleep, adding objective measures (actigraphy or biomarkers, such as cortisol), may provide more detailed information on caregiver sleep. In this study, subjective, self-report measures of sleep quality were used, which may not be completely accurate, as caregivers may over- or underestimate their sleep quality. Research has found that participants who are chronically sleep deprived may not accurately assess their sleep (Unruh et al., 2008), therefore objective measures may help to support a participants' reported sleep quality. Adding information about why the caregiver awakens during the night would prove helpful in tailoring interventions and understanding the true nature of the disrupted sleep.

This study specifically focused on maternal caregivers of young children with BPD. Maternal caregivers are largely responsible for the child's care (Stewart, Ritchie, McGrath, Thompson, and Bruce, 1994); however, some fathers may also be involved in caregiving. For future studies, expanding the sample to include fathers or male (uncles, grandfathers, boyfriends, brothers) caregivers may be useful. Also, expanding to include a wider variety of diagnoses may help to identify the specific challenges of caregivers and differences or similarities in what may influence QOL (Mitchell, 1996). The use of different populations may allow for a larger sample size to be recruited.

## Acknowledgments

This project was funded by T32NR012715 from the National Institute of Nursing Research. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Funding was also provided from Leadership Education in Child-Health Nursing (LECHN)- Maternal Child Health Bureau (grant number T80MC09653, PI: A. Turner-Henson.

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